

The harmony of disability

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At first sight the word harmony does not seem to be one most people would associate with disability. Harmony has a very specific meaning in musical terms, the combination of notes to form sequences of chords which follow accepted patterns and rules. The New Oxford Companion to Music defines harmony as the element of agreement in music, as opposed to counterpoint, in which parts move against each other and thus represent the element of disagreement. In a more general sense the word harmony is used to mean the combination or adaptation of parts, elements or related things, so as to form a consistent and orderly whole. Synonymous words are peaceableness and concord (Concise Oxford English Dictionary). In this sense disability might be thought of as the antithesis of harmony — the incongruity and disagreements of human impairment being positively dysharmonious. It will be my purpose in this lecture to look at ways in which we can reduce or reverse this assumption and help to restore the harmony to disability. I will be looking at the limitations which society imposes upon disabled people and seeking specific strategies to reduce this handicap. Much of my own work has been concerned with music and the arts as instruments for this purpose, but there are other aspects of what we may broadly term the rehabilitative process which I would also like to explore.

The other word in my title — disability — also needs some comment. The World Health Organisation has carefully defined the words impairment, disability and handicap and these distinctions are widely used and agreed by those working in the field. My own clinical experience is mostly of physical impairment and the disability that results, but much of what I have to say applies equally well to those with mental illness and handicap, to the frail elderly and to those with the sensory impairments of blindness and deafness.

The concept of restoring harmony to people with disabilities is made more difficult because of the diverse nature of disability and the many different ways of looking at the problem. From a practical point of view physical disability falls into two broad groups. First congenital impairments such as cerebral palsy and spina bifida, most commonly with non-progressive disabilities which have been part of the perception of life from infancy and often do not limit life expectancy. Secondly acquired disability, also of two types — the acute disability of trauma

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and stroke and the progressive disability of chronic arthritis or chest disease, multiple sclerosis, motor neurone disease or muscular dystrophy in younger people. The onset of disability in these cases is unexpected and inexplicable and results in profound changes in perception of life which has to be recognised by all who are involved in the problem. These two groups pose somewhat different problems in terms of the timing and type of intervention, but both have similar difficulties in trying to maintain a sense of worth and self-esteem, which is a common theme running through much of what I have to say today. We must also remember that disability is a family problem and that our strategies for helping people with disabilities must include major considerations of individual choice and support for, and involvement of, the family and carers at all times.

I would define rehabilitation as a process by which one seeks to maximise an individual's potential in terms of physical, mental, emotional and social capacity. In this sense rehabilitation never ceases because one can always do something to help. The diagnosis and management of impairment is a medical responsibility, combined with the use of specific therapeutic techniques. Disability can usually be minimised by the provision of suitable aids and equipment and handicap demands manipulation of the environment to restore or achieve a place in society for the individual. These concepts can be applied equally well to a person with a progressive disabling condition as to someone recovering from a head injury, and in this sense rehabilitation is a continuing process.

There is no doubt that the achievements of many disabled people are much more limited than they might be, quite apart from obvious physical limitations. I suspect that lack of expectation and lack of opportunity are two of the most important. The potential of disabled people is often unrecognised. Relatives may feel that they should not be "stretched", that stress is bad for them and this results in over-protection and an emphasis on disability rather than ability. Sometimes this is still compounded by the unjustified assumption that physical disability is necessarily associated with reduced intellectual and cognitive function. Another factor is the severe difficulty in communication because of speech or language disorder which affects many disabled people and which causes immense frustration. Alternative methods of communication include not only new computer technology, but also some aspects of arts involvement. It is up to us to provide the opportunities for disabled people to find the most appropriate and rewarding ways of achieving some of these new-found expectations.

There are many activities in which disabled people have been outstandingly successful. The Paraplegic Games attract large numbers of people in international competition and those competing in the Special Olympics have shown a diversity of athletic potential that, once accepted, has shown us how meaningless the word handicapped can be. Many people's interests and talents lie more in the field of the creative arts and these also have much to offer to those with the more severe types of physical disability. Here too, many have overcome their disabilities to achieve wide recognition. One thinks of Izak Perlman, a victim of poliomyelitis, Jeffrey Tate (Principal Conductor at the Royal Opera House) who has spina bifida and had just been made President of the Association for Spina Bifida and Hydrocephalus in England, and Evelyn Glennie, a virtuoso percussion player in spite of being profoundly deafened at the age of twelve. In the world of literature we record the achievements of Christopher Nolan and Christy Brown, both

profoundly disabled by cerebral palsy, Stephen Hawking and Ivan Vaughan with chronic progressive neurological disease, and Feodor Dostoevsky and Gustave Flaubert, both incorporating their disability of epilepsy into novels.

It will not be given to many to achieve at this level, but the important point is that artistic talent is not the prerogative of the able-bodied, that creativity is not related to intelligence and that specific disabilities may not be as limiting as they appear. Sometimes this leads us to strange concepts — for instance, the belief that deafness is no bar to music. I have recently been working with a professional musician who was born with profound hearing impairment and has a sister similarly disabled. However, Paul was brought up in a musical family and he makes the point that being born with musical interest and ability is nothing to do with hearing — perhaps more a question of how the brain is wired up. Paul started to play the piano at an early age and had no difficulty in learning to read music (which again as a process does not depend on hearing). He began to learn the organ at age 14 and in due course applied to read music at University level. Four departments of music turned him down without interview, but Oxford had the foresight to realise that if a deaf person wanted to read music he must be given a chance to prove himself, and they found him to be one of the best students of his year. Paul has virtually no useful hearing, and hears practically nothing of what he plays, but is now an organist and choirmaster in Huddersfield and spends much of his time promoting the idea of music with deaf people. I have dwelt at some length on this story to emphasise again that we should be looking at people's ability, and not allow disability to carry with it unjustified assumptions about inability.

This is part of the philosophy behind the *SHARE-MUSIC* courses which we have been developing over the last few years. *SHARE-MUSIC* aims to give physically disabled young people an opportunity to share a wide variety of musical activities with able-bodied colleagues and helpers under the guidance of expert tutors. We share not only our skills and talents and enthusiasm but also our resources and social activities by making all the courses residential. We insist on having at least an equal number of helpers (many of whom are skilled musicians or students) and disabled people, and the courses have an important educational component for the helpers, who learn about the problems of disability in practical terms. We would always have a mixture of people with profound and mild disability and we do not look for any particular musical expertise although playing an instrument even at a simple level is a help. The emphasis of the courses is on creative music-making in groups and we usually put together a piece of music theatre which is entirely created by the participants themselves and leads to a final performance to a small public audience. We provide an enormous range of orchestral and school percussion instruments as well as pianos, electronic keyboards and computers.

In Northern Ireland we have also had the opportunity to use the Gamelan, a collection of instruments from Bali, owned by Queen's University and have found these particularly suitable for disabled people to play. With such a variety of resources we can always find some way in which people can contribute, no matter what their physical difficulties. In this sort of environment we see disabled people exploring ways in which they can express themselves and making discoveries, finding talents and abilities that they were not aware of, and developing ways of communicating with people in musical terms, when more conventional means of communication are sometimes denied them. For those with very severe

disability the introduction of computers with MIDI-linked keyboards has opened a new world of music-making. In the last two courses we have provided a fully equipped workshop running a system called Midigrid developed in the department of electronics at York University. This system requires no knowledge of conventional music notation and is activated by moving a "mouse". For those who cannot even do that, there is always an alternative way and two of our most disabled young people have become skilled at programming a keyboard or a drum machine with one foot and are in this way able to provide backing for a whole musical sequence.

An interesting feature of these courses has been the tendency for disability issues to feature prominently in the creative projects of the students. In 1988 a lady with severe limb deformities produced a simple song she had written about a young friend who was a ballet dancer and suffered a sudden paralysis from the waist downwards, putting an end to her career. The poem compared the threads of life to those of the weaver and emphasised how tenuous they are and how easily broken. A whole music theatre project lasting 25 minutes was built round this idea. Another student who had lost both legs from progressive disease wrote a song entitled "The incredible shrinking man". People's ability and desire to express their problems in artistic ways (musical, dramatic, visual or even in poetry) is part of the enrichment which the creative arts can bring into the lives of disabled people. Some might even regard it as therapeutic although we make a point that *SHARE-MUSIC* is not a course in or of music therapy.

The special relationship and potential of the arts for and with disabled people was recognised by the Attenborough Committee, set up by the Carnegie Trust, which produced a far-reaching report in 1985. This recognised that the arts are for everyone, not just the privileged few . . . "To some degree it is within everyone's capacity to reinterpret their own experience and to share the experience of others by involvement in the world of art". The Committee took evidence from all parts of the UK and made some specific recommendations with regard to Northern Ireland, among which was that a pilot project should be set up to make recommendations as to how the arts and disability issue should be developed and co-ordinated in the province. With the help of the Northern Ireland Council for Disability and financial support from the Carnegie Trust, we appointed a part-time project worker about a year ago. As Chairman of the Steering Group, I have been specially concerned with this work and we have collected a large amount of data about what is going on in Northern Ireland. The brief of the project includes the setting up of a number of workshops in related topics, the first of which was held recently, concerned with access to arts venues. A lot of interest was shown in this, and we hope in due course to produce an access guide to arts centres, theatres, museums and cinemas in Northern Ireland. We are also interested in the potential of the community arts in relation to disabled people, and the Project Officer has been able to introduce artists with an interest in this work to local groups who are seeking help with specific projects.

Another particular interest of mine has been in the hospital arts. The Hospital Arts Movement started in Manchester some 15 years ago, and the Health Authority there now have several full-time artists working in health care settings. A department called Arts for Health was set up at Manchester Polytechnic last year and is in touch with over 230 hospital arts projects in Great Britain. One of these, I am

pleased to say, is in Belfast where we have now appointed an Artist in Residence to the Royal Group of Hospitals. The terms of reference of this post will be to enrich the total environment of the hospital by the introduction of arts activities of all sorts, to involve staff at all levels, visitors and patients as far as possible, and to liaise with local community groups and schools to bring their skills into the hospital environment. The underlying philosophy is that the arts can make a very positive contribution to health care and can encourage and hasten the healing process. The project at the Royal is being developed in association with the Arts Council of Northern Ireland, with major funding from the Gulbenkian Foundation. The DHSS has also contributed to the scheme and is itself setting up an advisory service to encourage other hospitals to explore the potentials of arts programmes. The performing arts are, of course, included in this programme and we have already held a number of lunchtime musical events in various parts of the hospital.

Music in hospitals is not, of course, new. Edward Elgar was appointed Music Director at the Worcester County and District Lunatic Asylum in January 1879. He was required to spend one day a week at the hospital and to direct the resident band which was mostly made up of hospital staff. He received a salary of £30 per annum, five shillings for each quadrille he composed and one and sixpence for every Christy minstrel accompaniment he arranged. He held the post for five years. Since 1947 the Council for Music in Hospitals has been promoting live concerts by professional musicians in hospitals, hospices and other institutions. In 1988 over 2000 such concerts were given in England and Scotland, and we have presented a number of tours by these musicians in Northern Ireland. The last was in August of last year when I myself joined two singers from the Council as accompanist and we gave eight concerts in five days in hospitals all over the Province. Another similar organisation is Live Music Now, which employs young professionals at the start of their career, and we have been exploring the possibility of extending their work to Northern Ireland. All this is in addition to the contribution which our own musicians, especially the groups from the Ulster Orchestra, make towards bringing live music into the hospital environment. There is abundant written evidence of the power that music has to stimulate the withdrawn, to awaken memories in the confused, to calm the anxious and to enrich the experience of people who are in threatening and sometimes uncongenial circumstances.

I have made little mention of the arts as therapy — another area in which I have been particularly interested, specially in relation to music therapy. I have been a member of the British Society of Music Therapy for many years and have recently been invited to be a Vice President. For the last two years I have been an examiner for the Music Therapy Diploma Course held at the Guildhall School of Music in London and from personal knowledge I have great regard for the dedicated work of Music Therapists. While traditionally much of their work has been with disabled children and with long-term mental illness and handicap, there is now an interest in exploring how music can help in other fields. One of the problems in relation to the creative arts as therapy is the question of evaluation. In the past there has been an emphasis on anecdotal evidence of benefit, but there is now a need for more objective evidence of effectiveness if scarce resources are to be used in this way. The need for research in music therapy has been recognised, particularly by the City University in London where a research fellow is appointed each year.

The present holder of the post is investigating the use of music therapy with Aids victims. Another research music therapist is working in the brain injury unit at the Royal Hospital & Home in Putney, investigating the part that music can play in the coma arousal programme in head injured patients and whether music can help the physiotherapist with the restoration of function to stiff and paralysed limbs.

Music therapy has been very slow to make its mark in Northern Ireland. One music therapist has been working in the Eastern Health Board for many years and another has recently been given a research grant to support her work with speech and language delayed children at Thornfield School. The Parkinsons Disease Society has supported some work to investigate how music can help people with this condition and some of the encouraging results might well be extended to other progressive disabling diseases. One or two students from Northern Ireland go to train in music therapy each year in London, but unfortunately we have not had the posts here for them to return to. However, a proposal to develop a Music Therapy Trust in Northern Ireland is now under way and we hope this will provide a focus for education and research, for the appointment of music therapists and for raising funds to support this work.

This sort of approach to disability does not easily fall within the thinking of doctors working in clinical medicine, who are trained to evaluate disability — its cause, diagnosis and treatment. The hidden ability, which everyone possesses no matter how severely incapacitated, may elude us. Only recently has the concept of looking objectively at the quality of life emerged as an important element in an overall view of health care. Oliver Sacks expresses it with characteristic insight “ our tests, our approaches only show us deficits, they do not show us power; they only show us puzzles and schemata, when we need to see music, narrative, play, a being conducting itself spontaneously in its own natural way”. Sacks speaks of the power of music in many of his writings, of its capacity for making people whole — a concept which has been with us at least since the time of the Greek philosophers. An important principle contained within the government paper “Caring for People” is the prominence given to a flexible system in which client choice and satisfaction are an integral part of the delivery of care. The Arts can make a positive and enriching contribution to restoring this harmony to disability.

In concluding I would sound a word of caution. Some people with severe and sometimes progressive disability seem to have within them a spiritual strength and tranquility which sustains them in the face of insuperable difficulties. The phrase “The harmony of heaven and earth” embraces the concept of bodily and spiritual unity and for some disabled people this inner resource may be sufficient to give them a purposeful and fulfilling life. We should consider whether we are justified in imposing our own ideas about quality of life upon them. We should recognise that some people achieve their own secret harmonies without our intervention — perhaps it is given to them to hear the Music of the Spheres, or the Song of the Angels — and we should remember that these issues should be handled with sensitivity. Our role is to encourage and to enable disabled people to lead as full and as meaningful a life as they wish within the constraints imposed by our present social customs.

The World Health Organisation in its manifesto "Health for All by the Year 2000" sets 38 targets for the European Region. The third of these reads "... by the year 2000 disabled people should have the physical, social and economic opportunities that allow for at least a socially and economically fulfilling and mentally creative life". This is a message with which all of us undoubtedly agree.

The Jim Egar Memorial Lecture is given at the invitation of NICOD and commemorates the life and work of Mr J J Egar who died in 1964. He was founder, secretary and treasurer of the Northern Ireland Spina Bifida and Hydrocephalus Association, and Vice Chairman of NICOD for 10 years. He was awarded the MBE for his services to the community.